



Burden of Poor Health Conditions and Quality of Life in 656 Children with Primary Immunodeficiency

Submitted by Beatrice Guillaumat on Wed, 08/28/2019 - 12:32

Titre	Burden of Poor Health Conditions and Quality of Life in 656 Children with Primary Immunodeficiency
Type de publication	Article de revue
Auteur	Barlogis, Vincent [1], Mahlaoui, Nizar [2], Auquier, Pascal [3], Fouyssac, Fanny [4], Pellier, Isabelle [5], Vercasson, Camille [6], Allouche, Maya [7], Brito De Azevedo, Carolina [8], Moshous, Despina [9], Neven, Benedicte [10], Pasquet, Marlène [11], Jeziorski, Eric [12], Aladjidi, Nathalie [13], Thomas, Caroline [14], Gandemer, Virginie [15], Mazingue, Françoise [16], Picard, Capucine [17], Blanche, Stéphane [18], Michel, Gérard [19], Fischer, Alain [20]
Editeur	Elsevier
Type	Article scientifique dans une revue à comité de lecture
Année	2018
Langue	Anglais
Date	Mars 2018
Pagination	211-217.e5
Volume	194
Titre de la revue	Journal of Pediatrics
ISSN	1097-6833
Mots-clés	Adolescent [21], Child [22], Child, Preschool [23], Cohort Studies [24], Cost of Illness [25], Female [26], Follow-Up Studies [27], France [28], Health Status [29], Humans [30], Immunologic Deficiency Syndromes [31], Male [32], Prospective Studies [33], Quality of life [34], Registries [35], Surveys and Questionnaires [36]

	<p>OBJECTIVE: To gain insight into how primary immunodeficiencies (PIDs) affect children's health status and quality of life.</p> <p>STUDY DESIGN: The French Reference Center for PIDs conducted a prospective multicenter cohort that enrolled participants who met all criteria: patients included in the French Reference Center for PIDs registry, children younger than 18 years, and living in France. Participants were asked to complete both a health questionnaire and a health-related quality of life (HR-QoL) questionnaire. A severity score was assigned to each health condition: grade 1 (mild) to grade 4 (life-threatening). HR-QoL in children was compared with age- and sex-matched French norms.</p> <p>RESULTS: Among 1047 eligible children, 656 were included in the study, and 117 had undergone hematopoietic stem cell transplantation; 40% experienced at least one grade 4 condition, and 83% experienced at least one grade 3 or 4 condition. Compared with the French norms, children with PID scored significantly lower for most HR-QoL domains. Low HR-QoL scores were associated strongly with burden of poor conditions.</p> <p>CONCLUSIONS: Our results quantify the magnitude of conditions in children with PID and demonstrate that the deleterious health effects borne by patients already are evident in childhood. These results emphasize the need to closely monitor this vulnerable population and establish multidisciplinary healthcare teams from childhood.</p> <p>TRIAL REGISTRATION: ClinicalTrials.gov: NCT02868333 and EudraCT 2012-A0033-35.</p>
Résumé en anglais	
URL de la notice	http://okina.univ-angers.fr/publications/ua20113 [37]
DOI	10.1016/j.jpeds.2017.10.029 [38]
Lien vers le document	https://www.jpeds.com/article/S0022-3476(17)31378-1/fulltext
Titre abrégé	J. Pediatr.
Identifiant (ID) PubMed	29198545 [40]

Liens

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- [2] <http://okina.univ-angers.fr/publications?f%5Bauthor%5D=37314>
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Publié sur *Okina* (<http://okina.univ-angers.fr>)